

July 2021

Accumulations of (Not) Doing

Richenda Cope
University of Massachusetts Amherst

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Accumulations of (not) doing

A Thesis Presented
By
Richenda Marie Cope

Submitted to the Graduate School of the University of Massachusetts in partial fulfillment
of the requirements for the degree of

MASTER OF FINE ARTS

May 2021

Department of Art

Accumulations of *(not) doing*

A Thesis Presented
By
Richenda Marie Cope

Approved as to style and content by:

Susan Jahoda, Chair

Shona Macdonald, Member

Kimberlee Pérez, Member

Juana Valdés, Member

Young Min Moon, Graduate Program Director
Department of Art

Shona Macdonald, Department Chair
Department of Art

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ABSTRACT

ACCUMULATIONS OF (NOT) DOING

MAY 2021

RICHENDA MARIE COPE, B.A., HAVERFORD COLLEGE

M.F.A., UNIVERSITY OF MASSACHUSETTS AMHERST

Directed by: Professor Susan Jahoda

As I encounter life during a global pandemic, caused by a virus that has us all homebound, I continue my own struggle with a different virus that keeps me not only homebound, but bed bound as well. In this thesis project, I *make* my way around and through the questions of chronic illness, self-worth, productivity and a changing relationship to time that arise in this dual viral experience - situating the personal within a larger social/political context.

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CHAPTER 1

WARM (UP)

As I sit in my living room by the wood stove, I watch the light reflect off the snow and burst through the windows, adding cold warmth to all of the surfaces and textures inside. I decide that it was winter that made me fall in love with painting. The snow helped me to see the broader shapes comprised of hidden things, the coalescence of object and form. At heart I think I am a painter still, though it has been many years since I devoted myself to that practice. Now it is for colors and shapes that I find myself longing, as I am stuck, in my bed or on the couch, on these long inside days. Even in recent years as my work has moved towards sculpture, combining materials to create new bodies, it continues to be like painting. Now the content comes from the objects themselves, their social and political histories that speak about industrial processes, waste and labor. Since I have been sick, my materials have been limited to those of the convalescent, increasingly digital in their presentation, as the constraints of bed and the coronavirus dictate. The materials are words, the materials are fabric. But if I truly believed in the Life Instinct,¹ I might begin to think of my materials as the set of actions I must perform for the health of my body. Taking pills and tinctures three times a day, making sourdough bread and kitchari with ayurvedic spices, gentle yoga, short walks, and inordinate amounts of time watching Netflix/Amazon Prime/Hulu. I don't want these corporate words to be part of any document that comes from me, but the truth is that these have become part of my life project, thus they are my material too. Could I somehow combine crusted sourdough starter with the blue light of the screen flickering on my tired face? If I had the energy, I might just be able to do it. I think I would create a suit that a body could step into, wrapped in all the pieces of a day with an audio track, singing songs of frustration, stiffness, depression, fatigue, digestive discomfort and boredom. I have been a maker of many kinds in my life: musician, puppeteer, poet, carpenter in addition to painter and sculptor. I am always seeking ways that these elements might come together. I want to weave them all into a whole that you could step into, passively participating in an expression of disparate parts that sing together in sometimes awkward, sometimes beautiful arrangements.

Awkward is an awkward word. I like it for that. So let it be my banner in this time.

I am in a place of awkward acceptance – yearning towards graceful – of the things I cannot do. It's a daily triage of priorities, a balancing of

¹ Ukeles, Mierle Laderman. "Manifesto for Maintenance Art 1969! Proposal for an exhibition 'CARE'." Accessed December 6, 2020. https://www.queensmuseum.org/wp-content/uploads/2016/04/Ukeles_MANIFESTO.pdf. For further discussion, see *Say*, pg 13.

energy with responsibility and desire. If I were to make that sculptural suit, I wouldn't be able to do yoga or make bone broth and the next day would have even less spoons.² I have begun to realize that the daily triage is not so much about which tasks I can or can't do, as it is about the balance of productivity. Making a thesis and culminating project of three years study pushes this tension to the max. The system in which I choose to take part asks me to produce something. As does my own sense of self – a child raised under capitalism; my self-worth wrapped up in the ability to make and do, to accomplish and shine. If it were just these external forces, I might have been more successful at climbing out from under this yoke, I might already be in that place of graceful acceptance. But there is also the me of me, the question of my own life force. If ever I was unsure, after two years of full-on battle with the forces of internal and external energies, I now *know* that my life force comes from making, from combining leftover materials to make new wholes.

So where does this leave me?

Awkward. Trying to accept what I do not want to accept. Rather than repairing objects cast off by a system that does not love them, I need to repair my own body, a body mangled by trying to make it in a world that does not hold with integrative care and living systems. What do I do? What (don't) I do?

I am trying, every day, to understand this time as a fallow field in which things can settle and reconstitute, thinking of my body and life as a place that is in hibernation, not ready to grow new crops. But the me that lives to make and the me that lives under capitalism, that knows myself as worthy through my ability to produce, continually bucks the metaphor. And metaphors can be dangerous.

Is it rather a process of tricking myself into thinking that my materials are sourdough, my materials are yoga and kitchari, enough water, turmeric and Monolaurin? Tricking myself that the painting I make is my body – new-made 38 year old white cis woman living with chronic active Epstein-Barr – until I actually believe it? Help me Mierle Laderman Ukeles. I need to believe that my life can be the painting in order to make it with gusto.

Some days I do believe. There are times when it is enough to start a soup stock, to wash the dishes, sweep up and change my sheets, to water the plants. I move through these tasks slowly and enjoy the feel

*"...illness is not a metaphor...the most truthful way of regarding illness – and the healthiest way of being ill – is the one most purified of, most resistant to, metaphoric thinking. Yet it is hardly possible to take up one's residence in the kingdom of the ill unprejudiced by the lurid metaphors with which it has been landscaped."*³

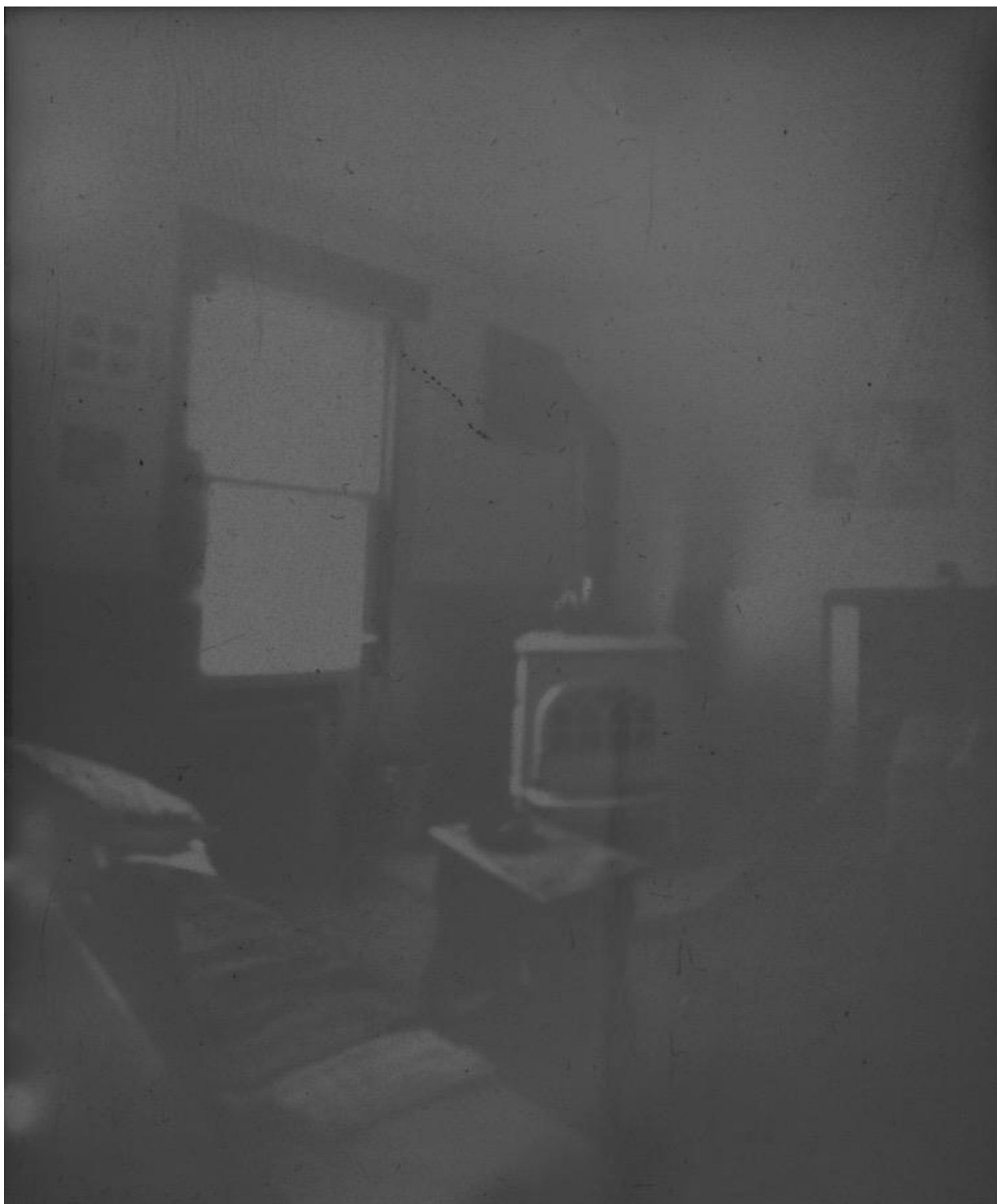
-Susan Sontag

²Christine Miserandino, "The Spoon Theory." But You Don't Look Sick. 2003. <https://butyoudontlooksick.com/articles/written-by-christine/the-spoon-theory/>. For further discussion, see *(Can't) See*, pg 5.

³ Susan Sontag, *Illness as Metaphor and AIDS and Its Metaphors*. New York: Picador, 2001, 3-4.

of the objects and my hands as they mingle. But other days I resent these tasks for the energy they take, for the absence of the painting. On these days my self-worth tanks, my belief in life and possibility are gone. When I try to work through it, I am a hamster on the wheel, circling back around again and again – *maybe if I, ooh or what I should do is, I think the thing is, the plan should be...* On these days the best is to shut it down. Hibernate. If I can't nap, I sew. I put on a book on tape and get into my bed with the quilt that I started piecing together by hand two years ago, shutting out the world both internal and external. And I quilt my way through to the next day in hopes that it will feel like a place of possibility. This thesis project is a process of believing it and all of the things I do when I don't – what eases and soothes, what rankles and stabs, how to create the painted object of my life in such a way as to hold me, not *so that*, not just to get through to the other side, but as *part of*.

So: life as painting. A day as a canvas. Medicines as pigment. Assemble, swath, excite, wipe out, again.



1. *untitled*, 3"x4", photo on paper, 2021

CHAPTER 2 (CAN'T) SEE

Try to tell myself I am tired because I'm sick, not because I'm lazy, not because I'm depressed.

I have Chronic Active Epstein-Barr, a virus that has been called a Trojan Horse. As in the Greek myth, EBV takes advantage of misdirection to slip in the back door.⁴ Which is to say, it most often shows up when your body is fighting something else. In my case this was most likely prolonged exposure to mold combined with extreme stress. Epstein-Barr writes itself into the DNA of other immune cells like the common cold or strep, so that when those cells replicate, so too does EBV. Then when your immune system is wiped out from dealing with the primary infection, EBV is there to take over. It's a virus, meaning that it will never leave your body. Though the *active* part may go dormant, I will always need to take care so that it doesn't keep swooping back in. As Joanna Hevda puts it in their *Sick Woman Theory*, "a chronic illness is an illness that lasts a lifetime. In other words, it does not get better. There is no cure."

In 2003 Christine Miserandino developed "The Spoon Theory" in an attempt to explain to an able-bodied friend what it was like to live with Lupus. They were in a restaurant, so she borrowed spoons from other tables and handed them to her friend, explaining that the spoons represented the amount of energy she had for the day. As the friend talked through her day, Miserandino took spoons away from her, demonstrating how each of these actions takes something out of you. Even small invisible actions such as *get (up)*, require a spoon.

EBV, along with most chronic illnesses, falls into a category of invisibility. While we avoid discrimination based on visible impairments, there is a different struggle here. The invisible nature of it makes it well, invisible. *But You Don't Look Sick.*⁵ We do not match up to the understood vision of a sick person. Our illness is something that needs to be explained. The environmental factors that often trigger our illnesses are unseen. People and systems don't understand why we can't keep up with expected deadlines, sit through long meetings, always have to cancel at the last minute, go anywhere that isn't our bed.

Like the virus itself, EBV's symptoms are slippery: achiness, digestive discomfort, extreme fatigue. Like so many chronic illnesses, it can be difficult to diagnose.

"I think she was starting to understand when she theoretically didn't even get to work, and she was left with 6 spoons. I then explained to her that she needed to choose the rest of her day wisely, since when your "spoons" are gone, they are gone."⁶

These chronic illnesses are thought to be triggered by either environmental irritants or an immune system confused as a result of overly hygienic environments and are not mental illnesses. However, because they often resemble other

⁴ Andrew Whitfield-Cook, "Epstein-Barr Virus: Part 1 with Dr. Mark Donohoe." *FX Medicine*. Podcast audio, May 10, 2017. <https://www.fxmedicine.com.au/content/epstein-barr-virus-part-1-dr-mark-donohoe>

⁵ Miserandino, "The Spoon Theory."

⁶ Ibid.

illnesses, are hard to diagnose, and three quarters of those afflicted are women, they have historically been wrapped in discourses of feminized hysteria and hypochondria.⁷

I wish I had had this sharp insight from curator and educator Taraneh Fazeli on hand when I spoke to a doctor who recommended that I try Cognitive Behavioral Therapy. The American Psychological Association's website describes CBT in the following way:⁸

Cognitive behavioral therapy (CBT) is a form of psychological treatment that has been demonstrated to be effective for a range of problems including depression, anxiety disorders, alcohol and drug use problems, marital problems, eating disorders and severe mental illness. Numerous research studies suggest that CBT leads to significant improvement in functioning and quality of life. In many studies, CBT has been demonstrated to be as effective as, or more effective than, other forms of psychological therapy or psychiatric medications.

CBT is based on several core principles, including:

1. Psychological problems are based, in part, on faulty or unhelpful ways of thinking.
2. Psychological problems are based, in part, on learned patterns of unhelpful behavior.
3. People suffering from psychological problems can learn better ways of coping with them, thereby relieving their symptoms and becoming more effective in their lives.

CBT treatment usually involves efforts to change thinking patterns. These strategies might include:

* Learning to recognize one's distortions in thinking that are creating problems, and then to reevaluate them in light of reality.

In the light of reality

EBV is not a mental illness. It is a virus attacking my immune system, that if unattended can lead to organ failure, forms of cancer and other

⁷ Taraneh Fazeli, "Notes for 'Sick Time, Sleepy Time, Crip Time: Against Capitalism's Temporal Bullying' – in Conversation with the Canaries." *Temporary Art Review*, May 2016. Accessed December 6, 2020. <http://temporaryartreview.com/notes-for-sick-time-sleepy-time-crip-time-against-capitalisms-temporal-bullying-in-conversation-with-the-canaries/>.

⁸ "What is Cognitive Behavioral Therapy," American Psychological Association website. Accessed April 29, 2021. <https://www.apa.org/ptsd-guideline/patients-and-families/cognitive-behavioral>. Screenshot by the author.

autoimmune conditions. I don't need to recognize my "faulty, unhelpful ways of thinking." If anything, I need CBT in order to **believe what my body is telling me**. I need it in order to confront the reality that I can't do what I used to be able to do. I need to recognize that any "distortions in thinking" are conditions of growing up in a capitalist culture that privileges the workings of mind far above the needs of our bodies.

*If one more person says, yeah I'm feeling so tired too I will fucking scream. Do you know that when you say this it's like pulling the keystone out of the arch I have been carefully building to try and understand that this is real. Not to be special or different but so I can BELIEVE it.*⁹

I know that you are tired. That deserves its own space –

we are tired
we work so hard
for a system that does not love us
how can we work a little less¹⁰

I will help you hold space for your tired if you will help me hold space for mine.

Far and away, my greatest adversary in this is my own mind. Not only is my illness invisible to others, it is also invisible to me. The changes in my body are not visible. Weight gain or loss depending on the month, muscles a little weaker, pale skin, tired eyes. Chronic Active Epstein-Barr Virus is not typically accompanied by a lot of physical pain. It is expressed in overall fatigue, digestive discomfort and achiness, lots of *ish* symptoms.

*"Illness is the night-side of life, a more onerous citizenship."*¹¹

On the good days I am grateful that I don't experience more pain. But sometimes in the private dark of the bad days I have wished for more pain, thinking this might help me to believe.

The pain comes from not believing. The pain comes from the conditioned responses of my mind.

*am I sick,
am I just
depressed,
maybe I just
need to...*

⁹ Chenda Cope, *Daily Notes* – 2/6, 2020-21, text on paper, 8 ½ x 11".

¹⁰ Chenda Cope, "an art of care/a cart of air" (unpublished poem, December 2019), typescript.

¹¹ Sontag, "Illness as Metaphor," 3.

How many times/ways can I tell myself that I am sick before I believe it?

*Many times.
Many ways.*

This thesis project is a collection of the ways that I show myself to myself, a documentation of daily life as proof of my changing body. I strive to make the work my life and my life the work. Not as metaphor but as actual. Every verb is a kind of *making*. I *make* my life through all of these actions. There are different steps and orders but they are always cycles, loops feeding back into one another.



2. *Embroidery*, dimensions variable, video still, 2021

CHAPTER 3 MAKE

Stew: chop each ingredient, add it to the simmering pot

Document: what I do, by order and time of day

Name: each verb, each action

Count: each verb, each action

Record: the passage of time through changes in the light

Write: approach, pull back, draw closer

Edit: add, change, subtract, repeat

Stitch: embody the words - suture myself to the present to make it through to the next day

Process: where the time goes

Make: put together from components: CONSTITUTE.¹²

Each verb is a kind of making. Each action, each component, constitutes my life each day.

"how the world has changed its shape"¹³

Though it was not my intention as I began this project, the work has become a kind of archive of my experience of time as a chronically ill body.

Crip time is the world shrunk

it is needing everything in arms reach

The archive has specific connotations - a collection of public records or historical objects, a museum, a special collection, a courthouse basement full of files. In *An Archival Impulse* art historian Hal Foster writes about the form within contemporary art, focusing on "... archival artists (who) seek to make historical information, often lost or displaced, physically present."¹⁴

I am held here in the reality of my body

To make physically present that which has been lost or displaced.

Who knows where the time goes?¹⁵

The source material for this archive is not public or historical. It is not the thing you will find in a special collection. But in building it, the archive itself begins to ask the question. *Why not?* Why aren't these kinds of private archives made public? What happens when we make the private chronically ill body public?

¹² Merriam-Webster.com Dictionary, s.v. "make," accessed May 25, 2021, <https://www.merriam-webster.com/dictionary/make>.

¹³ Virginia Woolf, *On Being Ill*. (Ashfield: Paris Press, 2012), 8.

¹⁴ Hal Foster, "An archival impulse." *October* (2004), 4.

¹⁵ I can't stop listening to Eva Cassidy's cover of Sandy Denny's *Who Knows Where the Time Goes*. Only recently did I remember that she was already living with the knowledge that she would soon die of cancer.

In “A Burst of Light”, a text about living with liver cancer, poet Audre Lorde writes:

*I think of how important it is for us to share with each other the powers buried within the breaking of silence about our bodies and our health, even though we have been schooled to be secret and stoical about pain and disease. But that stoicism and silence does not serve us nor our communities, only the forces of things as they are.*¹⁶

Yes there are days when I don’t want to talk about it, days when sharing that *I am tired* just feels like complaining. I come by it honestly: stoicism and a high tolerance for pain run in my family; we poke fun at these traits in thinly veiled admiration. But who does my silence serve? Not my family, not me, not others who live with invisible chronic illness. My silence only serves *the forces of things as they are*.

¹⁶ Audre Lorde, “A Burst of Light.” In *A Burst of Light and Other Essays*, 40 – 133. (New York: Ixia Press, 2017), 117.

CHAPTER 4

SUSTAIN

My grandmother was raised in the depression. She was a mother of five, a high school biology teacher, semi-homesteader and environmentalist. She was quiet, never wanting to be at the center, always redirecting the conversation back to others. She made homemade ketchup without sugar. She saved grapefruit seeds to grind up and put in casseroles for nutrition. Helen, who used every single part of the chickens she slaughtered, who fell and broke one of her front teeth on the walk to my brother's wedding and kept right on going to attend the ceremony.

Somehow, these qualities of economy and stoicism are linked in my mind. Perhaps it is a confused version of what sustainability is; should our relationships to natural resources and our relationships to our own bodies mirror one other?

*Do not take up space.
Use what you have.*

What about an economy of emotion?
Is keeping quiet like treading lightly on the earth?

*"Litmus tests of
society's wellbeing,
our bodies are wise
and we need to
start listening."¹⁷*

- Taraneh Fazeli

And what about an economy of illness? The medical industrial complex that treats patients as dollar amounts, believing that there is a medical cure for what ails us.

There is also an economy of energy, of what we can and cannot do. Save your energy for the important things. But who gets to decide what the important things are?

But maybe the language is the problem. The common definition of economics is not the one that I want. In biologist and artist Robin Wall Kimmerer's *The Serviceberry: An Economy of Abundance*, she writes about the different meanings of the term. Most definitions of economy include the word scarcity: *With scarcity as the main principle, the mindset that follows is based on commodification of goods and services.*¹⁸ Kimmerer's essay is about gift economies, about building alternative ways of "organizing ourselves to sustain life."¹⁹ There are *other ways*. Other mindsets, other ways to sustain life.

¹⁷ Fazeli, "Notes for *Sick Time*."

¹⁸ Robin Wall Kimmerer, "The Serviceberry: An Economy of Abundance," *Emergence Magazine*, Dec. 10, 2020. <https://emergencemagazine.org/essay/the-serviceberry/>.

¹⁹ Ibid.

What would I trade my silence for? Accomplishment? A sense of pride? These things are the tightrope that I am already falling from.

There is a net.

We must make our own systems, our own economies. This is the *alternative knowledge* that we need, that we *already have*.

In building my own archive, I document the *(not) doing* as it is hemmed in by and resists ableist capitalism in equal turns. I witness my changing body, I examine my life. In documenting daily acts of maintenance and sustenance, they rise to the level of consciousness, noted and counted, making visible the invisible. Through building the archive, I offer my own self *other ways* of being.

*alternative
knowledge*

*counter
memories”²⁰*



3. *Chicken Soup*, dimensions variable, video still, 2021

²⁰ Foster, "An Archival Impulse," 4.

CHAPTER 5 SAY

mind from body

The Death Instinct: *separation*; individuality; Avant-Garde par excellence; to follow one's own path to death —do your own thing; dynamic change.

Strive to bring my body and my mind together. At this time my body has a very great need. Art practice is used as intermediary for mind to listen to body.

The Life Instinct: *unification*; the eternal return; the perpetuation and MAINTENANCE of the species; survival systems and operations; *equilibrium*.

-Mierle Laderman Ukeles²¹

Not yet achieved. Or really that reveals flawed thinking. Equilibrium is not achieved, it just is. In order to achieve equilibrium right now I must spend about 60% of my time in stillness. In this case equilibrium must mean something more like existence, just straight up life. Or maybe it should be life plus sanity.

4. *Drawing on The Life Instinct*, dimensions variable, digital drawing, 2020

I am tired.

Some days this means that I cannot think straight. Some days my mind is clear but my body cannot get up to do what my mind wants it to do.²¹ The word means something different each day, but the usage of it is consistent. I am *tired*, always so *tired*. In response to this ever-present declaration, my therapist asked me to define *tired*.

Tired is a throw away word, it's shorthand flattens experience. What does *tired* mean today?

Tired is: stillness verging on blankness

Tired is: in my eyes, my stomach,
a kind of dry achiness that peels back
from the shell²²

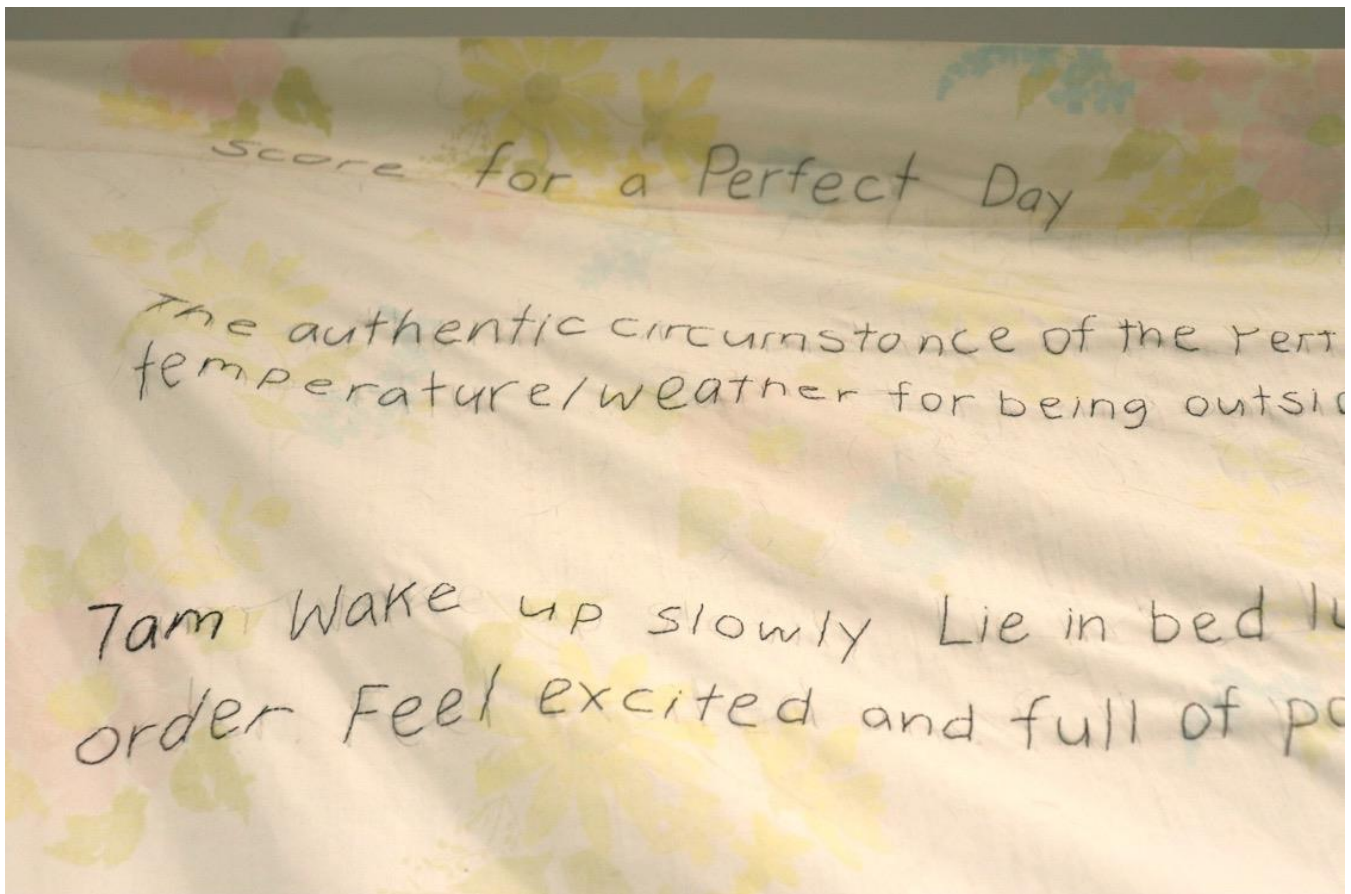
²¹ On the separation of body and mind, writer and disability justice activist Eli Clare writes of his choice of language: "I followed the lead of many communities and spiritual traditions that recognize body and mind not as two entities but as one, resisting the dualism built into white Western culture...I settled on *body-mind* in order to recognize both the inextricable relationships between our bodies and our minds and the ways in which the ideology of cure operates as if the two are distinct – the mind superior to the body, the mind defining personhood, the mind separating humans from nonhumans." Eli Clare, *Brilliant Imperfection*. (Durham: Duke University Press, 2017), xvi.

²² Chenda Cope, "Tired" (unpublished poem, April 2021), typescript.

With specificity, I get closer to the direct communication of my body; communication that is not of the language of words.

As I *make*, I translate and interpret what my body is saying. In this *making* I come to the realization *which will surely be forgotten and remembered at least twice by tomorrow* that my body has great wisdom that my mind has forgotten how to integrate.

I know I had this body knowledge once upon a time when I was a screaming baby – not having yet learned about capitalist time and its constraints, not having yet learned about being polite and not complaining, not having yet learned that not doing equals laziness. In order to get me in my conditioned state to listen, my body has had to scream. It has taken a lot of screaming until I began to listen. It's easy to look back now and think, *if only I had paid more attention two years ago, if only I knew then what I know now*. But that is another mind trap. One to politely or rudely, depending on the day, *shut down*. (See Appendix B: *Shut It Down*).



5. *Score for a Perfect Day*, 76" x 93", thread on sheet, 2021, detail

The text is written and edited many times over. The amalgamation of many days into one: Score for a Perfect Day. In a time of energy, I project and pencil the words onto an old bed sheet, faded pink and blue flowers with yellow green leaves. It's ready for me when I need it, when I need to Shut It Down, when I need it to survive. The fabric moves from couch to bed and back in a heap. The cat likes to nap on it. Her hairs get sewn in. To stitch is to embody the words – I suture myself to the present as it passes through to the next day.

CHAPTER 6 PRACTICE

I have always been both fast and slow: quick to form an opinion, impulsive to feel, but slow to understand what those reactions mean. The language of words comes quickly but I do not always understand what it means in my body. After the initial impulse and action, it takes me much longer to integrate the knowledge in my body.

As an artist, my practice is similar- I have an idea and I start making, discovering what it is through my response to materials. After time passes, I understand more what the thing is, and much of what I make falls by the wayside:

part of the soil, unseen, integral to the living thing that emerges

As a sick artist, my methods have had to change. I do not have the luxury of boundless energy to discover my way through making. It has taken me awhile to realize this. At the outset of this project, I still imagined the body of work that I would make as a former me – trying to express something of the out-of-time sick room through the hands of an able-bodied maker with ample spoons. I wanted to construct a paper maché cast of the inside of my room, a full scale 3-D sculpture made of scrap paper. Like Rachel Whiteread's casts, this sculpture would create the negative space of the sick room – *permeable and fragile, pressing and pressurized* – built up of many many layers of castoff materials. The sculpture would be installed outside so that it could dissolve over time in the rain and sun. I was so excited by this idea and lay awake more than a few nights thinking about how I would need to brace it and what methods I would use as release. It was almost a week before it dawned on me that this project was absolutely antithetical to my wellness – not only would it require being upright for many hours, it would entirely disrupt the haven of my sick room, the place that I needed to be reliably clean and available. It was this realization more than anything else that brought me to the place of knowing *which will surely be forgotten and remembered at least twice by tomorrow*.

*Remember not
to forget
about the
tiny layers
of every
thing. They
are thin,
flexible and
very heavy.²⁴*

After this first big realization came several smaller ideas – drawings from bed, capturing the still life through still life. Limit all works to only what can be done from bed. But after many failed attempts, this did not work either. Something in the attempt to coalesce, to express, felt wrong. *My body is a gauge.*²³ *Listen*. There was still a kind of forcing happening.

²³ Chenda Cope, "Time Spaces – Prologue" (unpublished play, December 2020), typescript.

²⁴ Chenda Cope, "My Material Body." *Midway and In Between*, edited by Jeff Kasper, 2020, 22.

If I listen to what my body says to my mind, it is saying: *We don't want to do anything. We are tired. You, mind, need to settle down. Those ideas can wait, and if they are good ones, they will. Or maybe someone else will do them. Or maybe not. The thing now is just to fucking rest.* And so, not only do my methods need to change, it is also my thinking that needs to change.

Yes/And: That is a lifelong project.

Yes/And: My life is the project. I make, not simply as a way to pass the time, but because it helps me to understand myself and the world around me. Furthermore, I have a deadline. I chose this path, I am part of the wheels and march of capitalism, achievement and production. Though I have questions, though I resist, I am still a part of that system and am still trying to make change from within it. The step towards an MFA is part of the life project and I want to complete this step.

Though many days my body is saying *no, the thing now is to rest*, I offer it another option - a chance to understand making as medicine, as healing. This is a place I know. That space outside of words that happens when my body is moving with my materials, even if they are words – that is deep medicine.

This project is the many acts of raising that deep medicine to consciousness, actions that echo in the spaces of *(not) seeing*.

CHAPTER 7

ASK

In order to show up here,
whose backs am I standing on?

Many many backs.²⁵

I cannot do this alone. I have and will continue to ask for help from many people. (See Appendix 1: *Support*).

Chapter 3 of Susan Jahoda and Caroline Woolard's *Making & Being* asks, "Who Do You Honor?" I honor the very asking of this question and its invitation to recognize support, to honor and name the people and bodies of wisdom that influence who we are. By doing so, we recognize that we are in relationship with these others at all times, even when they are not physically present.

This text is threaded with other people's words. Some of them are people I know personally. Many I never will.

In my introduction, I called on Mierle Laderman Ukeles for help. Her ground-breaking and still radically relevant 1969 *Maintenance Manifesto* came out of a need to integrate her life as a mother with her life as an artist. The separation of the two was an unsustainable violation and denial of her full self. It was from this lived experience and necessity for integration that she created a new framework for her life and work, developing her theory and practice of Maintenance Art:

I honor the multitudes of wisdom, integrating the words into my own writing, not to disappear their origin, but to recognize their vital role in my own making.

The elements of the world, like gravity, came crashing in, so you had to take care of things, and I was trying to avoid taking care. So, I sat down and I said, "If I am the artist, and if I am the boss of my art, then I name Maintenance Art." And really, it was like a survival strategy, because I felt like "how do I keep going?" I am this maintenance worker, I am this artist — I mean this is early feminism, very rigid, I literally was divided in two. Half of my week I was the mother, and the other half the artist. But, I thought to myself, "this is ridiculous, I am the one."²⁶

²⁵ Cope, "an art of care/a cart of air." These lines reference *This Bridge Called My Back: Writings by Radical Women of Color*. Ed. by Cherrié Moraga and Gloria Anzaldúa.

²⁶ Bartholomew Ryan, "Manifesto for Maintenance: A Conversation with Mierle Laderman Ukeles." *Art in America*. March 18, 2009. <https://www.artnews.com/art-in-america/interviews/draft-mierle-interview-56056/>

Prior to my diagnosis of EBV and what I now know was the first year of my illness, my artist's bio read as follows: "In form and content, her work is an exploration of care and crisis, asking/wondering/proposing how we can still take care of each other while living inside the pervasive web of capitalism and its ethic of disposability." And yet, when I wrote this, I was still avoiding taking care. My energies were going outwards, looking at all systems besides the one closest to me that was clamoring for my attention. The urgent step to be taken is to consider my own body as vital a system, a system in crisis that needs care and support as much as my loved ones, as much as my wider communities, as much as the earth.

There is a critical context for this kind of radical self-care. I have read it before and believed it true, *for other people*. But for myself, on some level I still felt it to be a kind of excuse, still managed to berate myself for not doing enough, not giving enough of myself. But if I am to live in my changing body, I have to learn the lesson that I *must* heal myself as a necessary part of any greater healing. There is an important distinction here. The phrase that wants to roll off my tongue is *so that*. But *so that* is still an assembly line, framed as a means toward a particular end. I choose instead, *part of*.

If I am to live in my changing body, I have to learn the lesson that I must heal myself as a necessary *part of* any greater healing.

Most of the language that I trust in the conversation around the politics of self-care comes from black, brown and writers of color. It is no accident that systematically oppressed communities have developed deep wisdom around survival. These wisdoms share a common thread - giving language to how there can be no individual healing without collective healing and vice versa.

I already have
what I need.

I just need to
look at it, I
just need to
listen to it,
I need to hold
it in my
hands.

Then I'd like
to give it
away. Except
for the things
I keep for
myself.²⁹

Black lesbian feminist poet Audre Lorde writes: "Black women who survive have a head start in learning how to be open and self-protective at the same time. One secret is to ask as many people as possible for help, depending on all of them and on none of them at the same time."²⁷ In addition to the survival of black women, her words speak of the permeability of the self and the other – the necessity to call on support networks, but also to be able to discern what it is that we need.

One of these black women who survived is Sonya Renee Taylor, author of *The Body is Not an Apology*. Her 2018 text is a guide and workbook for anyone and everyone who wants to engage in the healing work of radical self-love. Taylor begins her text with clear definitions. In her

²⁷ Lorde, "A Burst of Light," 122.

²⁸ Cope, "an art of care/a cart of air."

words, “radical self-love is a tool for social change.”²⁹ She distinguishes the work from self-care, which on its surface has many of the same practices and tenets. But self-care falls into a category with self-esteem, self-confidence and self-acceptance: the “ship(s)...aimlessly adrift at sea,”³⁰ always looking for a port, while the addition of *radical* speaks to the root, connecting us to community. “Radical self-love starts with the individual, expands to the family, community, and organization, and ultimately transforms society. All while still unwaveringly holding you in the center of that expansion.”³¹

Taylor’s words help me to rearrange my own thinking. Less: I need to take care of myself *so that* I can contribute to the larger healing that needs to happen globally, rather: my self-healing is *part of* the larger healing project. “Radical self-love is about the self because the self is part of the whole.”³² Yes and yes. Thank you for these expansive and generous words Sonya Renee Taylor.

Not only is the work to listen, but also to believe that I am worth it. That this small part of the whole is integral to the whole. Perhaps believing this will help me to listen and perhaps if I listen, I will believe.

“This is no longer a time of waiting. It is a time for the real work’s urgencies. It is a time enhanced by an iron reclamation of what I call the burst of light – that inescapable knowledge, in the bone, of my own physical limitation.”³³

Thank you Audre Lorde for your sharp brilliance. Thank you for your words that define urgency, reminding me what *inescapable* means, helping me to locate it in my body.

– *that inescapable knowledge, in the bone, of my own physical limitation.*

I honor one more contemporary black voice in this conversation: Resmaa Menakem, somatic practitioner, social worker and writer. In *My Grandmother’s Hands*, Menakem writes that “While we see anger and violence in the streets of our country, the real battlefield is inside our bodies. If we are to survive as a country, it is inside our bodies where this conflict will need to be resolved.”³⁴ He calls white supremacy *white-body* supremacy, drawing attention to *the body* as the place where trauma and the impact of centuries of racism live. *My Grandmother’s Hands* is a kind of self-help book, offering guided exercises, some for all bodies, some for black, white and law-enforcement bodies, respectively. The work of these exercises begins with simply paying attention to what comes up without doing anything at all. After the first somatic exercise offered, Menakem says:

²⁹ Sonya Renee Taylor, *The Body is Not an Apology: The power of radical self-love*, 2nd ed. (Oakland: Berrett-Koehler Publishers, 2021), xvii.

³⁰ Taylor, *The Body is Not an Apology*, 1.

³¹ Ibid, 10.

³² Ibid, 10.

³³ Lorde, “A Burst of Light,” 119.

³⁴ Resmaa Menakem, *My Grandmother’s Hands*. (Las Vegas: Central Recovery Press, 2017), xvii.

*Don't skip or skim the healing and grounding exercises in this book – ones with activities that help you remember your body...If you've already skipped the previous activity, stop. Go back and complete it before reading further. Don't keep reading and promise yourself you'll do the activity later. That's not how this book works. Before you read further, you need to experience the activity with your body.*³⁵

This directive is about the knowledge that only a body can know. If we skip the exercises and try to learn only what the words offer, we miss the essential wisdom that Resmaa Menakem's work teaches. He is telling us from *lived experience* that we cannot integrate the words to heal trauma without experiencing what is happening in our bodies. This is a powerful, in-action reminder of the necessity of integrating body knowledge with the knowledge of the mind.

Don't Skip Over This. Thank you Resmaa Menakem. This is a reminder that there is no true change, no true healing, without witnessing the body. If I listen, if I pay attention, my body will tell me.

(The rightness)

My body is a gauge. When it gets quiet, it gets to humming.
It gets down to the business of warm limbs and blood circulating through my vast inside.
That is when I know what the size is,
That is when I know what the height shape and texture are.

The rightness is not conditional but it goes into hiding.³⁶

³⁵ Menakem, *My Grandmother's Hands*, 30-31.

³⁶ Cope, "My Material Body," 22.

CHAPTER 8 (CAN'T) DO

Do Nothing Day ≠ tv series day.
Sometimes nothing = nothing
Sometimes nothing ≠ anything
Is nothing ≤ anything
Is nothing ≥ nothing at all
Is it a fraction?
*Search for the correct equation.*³⁷

In the Fall of 2020 when I was trying to figure out how I could possibly make this project from my impaired body, I cried during a meeting with my advisor. I just didn't have the energy to do anything. Susan suggested: *Take notes on your day, make note of yourself living your life. That's it. And we will see what emerges.*

On October 8, 2020 I began the *Daily Notes*, attempting to write down everything I did each day with approximate times. I wrote them on the back of a computer printout of the New York Times crossword puzzle, forwarded to me daily by my friend ESK (see Appendix A: *Support*). I had discovered over the summer that doing the crossword before bed and first thing in the morning had become a survival tactic, helping me ease in and out of the day, a thing for my mind to do in order to vanquish self-beration (see Appendix B: *Shut It Down*). I kept them on a clipboard hanging next to my bed. Rather than a journal or special paper, the back of the crossword was the ideal place to take notes because it was *easy* – it was just right there, a structure already in place; the economy of using what I already had. *Thank you Grandma.*

11am Go back to bed.

A tip:
Bring everything you can think of that you might want with you.

Once you are there you won't be able to get up unless it to piss shit or puke.

Not even if the thing you want is just on the other side of the room.³⁹

When I began the *Daily Notes*, they were a way to stay sane, to do something towards this increasingly impossible feeling thesis project. They were also reminiscent of actions I have taken in the past when in bouts of depression – a way to keep something moving, to be accountable to myself. But in this case, rather than a prescriptive set of actions that I tried to fulfill on a daily basis, they were the opposite – no need to do anything special, just take notes on what you do *do*. They were easy and at hand, no effort involved other than to listen to the day.

Crip time is the world shrunken

it is needing everything in arms reach

I am held here in the reality of my body

What is sustainability in an impaired body?

³⁷ Cope, "My Material Body."

³⁸ Chenda Cope, "Score for a Perfect Day" (unpublished score, January 2021), typescript.

the abundance of
the leavings:

trash, garbage,
compost, offal,
debris, detritus,
skin, bones,
footprints,
shells, traces,
imprints

what is left
behind⁴⁰

Questions of sustainability have always been part of my work: a recognition of abundance and waste, the desire to make without making anything new, to incorporate making into the lifecycle of existing materials. But like my former artist's statement, this work is about the sustainability of external systems, rather than my own internal ones.

How can I complexify the definition of sustainability, a term now wound up in Green Initiatives and better business jargon?

If I remove *ability*, I am left with *sustain*.
sustain: to give support or relief to, nourish.⁴⁰

Sustain the change;

...

*Keep the home fires burning.*⁴¹

I *sustain* myself through ease, through what is within reach. I learn to make the things that I need be the things I already have.

*"Slowing down ... is about inviting abundance thinking in the present and focus on our bodies now for its intrinsic value as a knowledge producer, rather than later, or for some other extrinsic value."*⁴²

These are the goals of the project that are (not) achieved.
I strive for the "*not do' approach*."⁴³

In addition to the quirks, scribbles and surprising poetic moments, the major discovery of the *Daily Notes* from October '20 - February '21, is how much I really was *doing*, when trying not to do too much at all.

I made an excel spreadsheet, extracting every verb and verb/preposition from each of the *Daily Notes* - making a chronological list of verbs performed each day as well as a master list with the number of times enacted. Within the envelope of my incomplete record keeping which always erred on the side of leaving things out, the verb

³⁹ Cope, "an art of care/a cart of air."

⁴⁰ Merriam-Webster.com Dictionary, s.v. "sustain," accessed May 25, 2021, <https://www.merriam-webster.com/dictionary/sustain>.

⁴¹ Ukeles, "Maintenance Manifesto."

⁴² Shahjahan, Riyad A. "Being 'lazy' and slowing down: Toward decolonizing time, our body, and pedagogy." *Educational Philosophy and Theory* 47, no. 5 (2015), 498.

⁴³ Ibid, 496.

master list includes 169 unique verb and verb/preposition combinations with 1072 total occurrences. I can't say exactly what this means. Clearly this study would not make it past any peer review. But I can tell you that that is still a lot of doing, even when it is a Do Nothing Day. A Do Nothing Day still includes, at minimum, *wake (up)*, *pee/poop*, *go (back to)*, *get (up)*, *make (food/drink)*, *go (back to)*, *get (up)*, *make (food/drink)*, *go (back to)*, even when you have a superstar roommate who brings you tea, soup and egg sandwiches. Not to mention that while lying in bed you will probably also *watch*, *text*, *do (crossword)*, even during the really blank times.

Verbs - October ☆ 📅 ☁												
File Edit View Insert Format Data Tools Add-ons Help Last edit was on March 12												
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A1	fx 10/8/2021											
	A	B	C	D	E	F	G	H	I	J	K	L
1	10/8	10/9	10/10	10/11	10/12	10/13	10/14	10/15	10/16	10/17	10/18	10/19
2	wake	wake	wake	wake	wake	wake	wake	wake	wake	wake	wake	wake
3	count	fall (back)	poop	lie (awake)	get (up)	deal (with)	pee	roll (around)	loll	fall (back)	lie (in)	pee
4	alternate	make (food/drink	sleep	pee	pee	go (back)	drink	send	make (food/drink	wake	stare	wake
5	do (crossword)	work (on)	read	get (up)	go (back)	work (on)	read	get (up)	go (to)	lie (in)	get (up)	lie (in)
6	turn (on)	fall (back)	heal	finish	fall (back)	shower	email	poop	make (food/drink	text	make (food/drink	sit
7	turn (off)	wake	wake	fall (back)	get (up)	start	do (yoga)	drink	talk	make (food/drink	go (back)	walk
8	lie (in)	stare	lie (in)	wake	go (back)	clean	clean	make (food/drink	clean	go (to)	fall (back asleep)	pick (up)
9	stare	think	think	stare	prepare	take (meds)	cut	go (back)	install	clean	wake	start
10	text	make (food/drink	make (food/drink	move	grade	drive	teach	read	clean	make (ink)	read	email
11	play	go (back)	drink		make (food/drink	mess (around)	drive	do (yoga)	meet	eat	talk	read
12	get (up)	work (on)	start	send	sit	eat	stop (at)	install	hook (up)	talk	clean	shower
13	pee	look	go (back)	get (up)	go (to)	make (dinner)	meet	brace	clean	sit	do (yoga)	teach
14	poop	lie (down)	zoom	make (food/drink	work (on)	leave	visit	make (food/drink	draw	move	shower	work
15	drink	quilt	email	go (back)	clean	do (can't)	teach	drive	quilt	get (in)	go (back)	get (in)
16	make (food/drink	get (up)	clean	work	prepare	clean	talk	hang (out)	watch	work (on)	spend (time)	make (food/drink
17	pour	take (mades)	make (bed)	analyze	teach	sit	drive	hang (out)	work (on)	sit	eat	work (on)
18	go (back)	make (food/drink	remove	grade	get (in)	talk	arrive	play		hang (out)	sit	quilt
19	do (crossword)	work (on)	take (break)	clean	watch	shower	research	drive				eat
20	start	make (food/drink	grade	talk	eat	eat	do (yoga)	watch				
21	work	pull	patch	make (food/drink	stay	get (in)						
22	get (up)	make (food/drink	sit	walk	make (food/drink	watch						
23	eat	sit	talk	zoom								
24	zoom	talk		clean								
25	make (food/drink	wander		get (in)								
26	eat	make (food/drink)										
27	drive	patch										
28	walk	wash										
29	sit	make (food/drink)										
30	drive	sit										
31	talk	stare										
32	measure	grade										
33	count											
34	put (away)											
35	start											
36	roast											
37	sit											
38	talk											
39	eat											
40	brush											
41	sit											
42	catch (up)											
43	clean											
44	quilt											
45	facetime											
46	do (crossword)											
47	sleep											

7. (not) doing, dimensions variable, screenshot, 2021

CHAPTER 9 DOCUMENT

The *Daily Notes* collect evidence. They build up proof that in fact, even on Do Nothing Days, I still do a lot.

My body is a gauge.

Listen when it says yes and also when it says no.

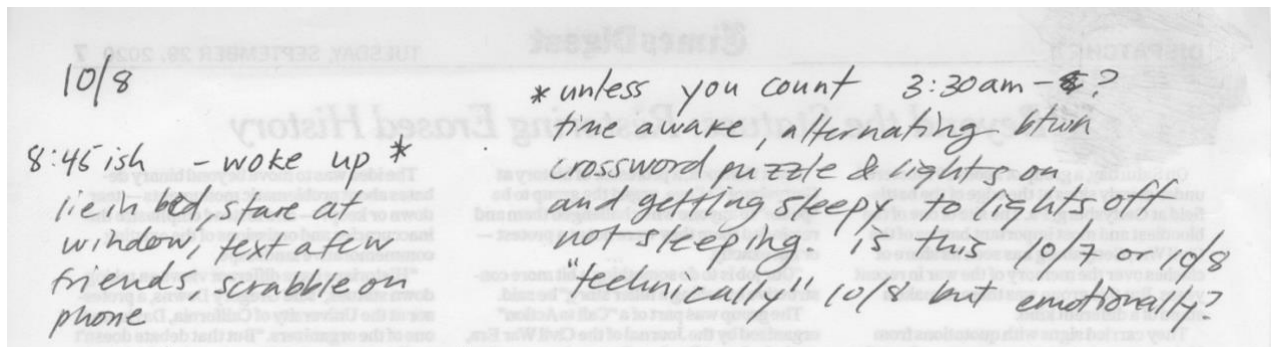
Yes is air and lift.

No is leaden constriction.

My collection of actions is akin to Mierle Laderman Ukeles' accounting for every single step in *Dressing to Go Out/Undressing to Come In* in which her husband documents her dressing their children for a winter excursion putting on a series of boots hats mittens jackets and subsequently removing them after the outing is done.⁴⁴ The documentation is not of the destination, not of the actual *going out*, but rather, the preparation.

If we were counting spoons they would never get out the door.

The notes attempt to be as record-like as possible, but they are already an edited object, including only what I remember and a sense of self-consciousness that the action is already an impossibility. This is present even on the first day of notetaking.



8. *Daily Notes* – 10/8, 8 ½" x 11", pen on paper, 2020

The addition of times is notable. This was not a conscious decision. Why did I need to do this? In a sense, I was still accounting for myself through capitalist time. I think of Tehching Hsieh's *One Year Performance: Time Clock Piece* in which he punched a time clock on the hour, every hour for an entire year.⁴⁵ This piece is a powerful statement about the confines of capitalist time and its infiltration into our lives. Limiting all actions, including sleep, to one-hour increments, bound by the time clocks hourly need.

⁴⁴ Mierle Laderman Ukeles, *Dressing to Go Out/Undressing to Come In*, 55" x 42 ¼", Ninety-five black and white photographs mounted on foamcore with chain and dustrag, 1973.

⁴⁵ Tehching Hsieh, *One Year Performance: Time Clock Piece*, dimensions variable, performance, 1980-81.

In a 2016 collaboration with the Canaries, an art adjacent collective of chronically ill individuals, curator, educator and fellow member Taraneh Fazeli offered Benjamin Franklin's daily timetable, as a kind of prompt. His timetable is precise, rising at 5am to wash and "contrive day's business", followed by work, meal, work, meal, "diversion" and sleep at 10pm. The day is flanked by questions. In the morning: "What good shall I do this day," in the evening: "What good did I do this day?"⁴⁶

Canaries members reinterpret the timetable through their own chronically ill bodies.⁴⁷ AKB blacks out half the page with marker, designating this area as "sleep" and Benjamin Franklin's question becomes: "Will there be chairs?" Park Macarthur's version turns the timetable on its side, a reference to being wheelchair bound, scribbling her name right over the numbers that run across the middle of the page. The reinterpretations are an undoing of standardized time, showing time as lived through the chronically ill body, visualizing the ways in which *sick time is non-compliant*.⁴⁸

*We are Canaries
in the coal mine,
seeking new
forms of address
through the
assertion of
vulnerability.*⁴⁸

Taraneh Fazeli's on-going exhibition *Sick Time* with a shifting cast of chronically ill artists, is an exploration of the chronically ill body as a site of resistance to capitalism. By collectivizing the act of, these projects "*hint(s) at how we might begin to tell capitalism to back the fuck off and keep its hands to itself.*" The works', stance is that it is the very inability to adhere to capitalist time that offers the chronically ill body "*a form of knowledge of imbalances in the world writ large.*"⁴⁹

Yes. My own *Daily Notes* are bound by the strictures of capitalist time. But they are not prescriptive. They don't adhere. *Sick time is non-compliant*. They may try, but they always fail. And the failure is as important as the success. In what began as a survival tactic, a-going-through-the-motions kind of action, the project turned into a sprawling organic journal in a time when I was struggling to express myself, expanding my connection to myself.

Benjamin Franklin's timetable is shared by websites and bloggers on time management, cited in the name of regularity and efficiency – qualities to lead us towards maximum productivity.

The *Daily Notes* take the opposite approach – documenting what *is* rather than what *should be*. They are not made in order to make change, rather they are a *slowing down* to observe what is already happening.

⁴⁶ Printed in Fazeli, "Notes for *Sick Time*."

⁴⁷ Jesse Cohen and Carolyn Lazard (with Canaries), *Notes for the Waiting Room*, 2017. Accessed December 6, 2020. https://static1.squarespace.com/static/537c9eb6e4b0ca838c2f4f52/t/5eaafc3bc2609667f6a9ae23/1588264038420/NFTWR_LincoV5.pdfpg 22.

⁴⁸ Fazeli, "Notes for *Sick Time*."

⁴⁹ Ibid.

2/6
 feel like I've been sleeping more and more which I guess
 is a good thing.
 what is the best way to think about this?
 a death? a death of old self
 would that almost be easier to step into
 no going back requiring complete
 transformation?
 I mean probably not. But in this case
 hope becomes toxic - impeding transformation
 I used to want to talk about the difference
 btwn joy & happiness. Now I want to think
 about hope vs. what? I'm not trying to
 say that all is lost but maybe hope is
 predicated on ideas/expectations - things that
 rip every rug out from under my shaky feet
 I don't even know how to approach a day newly.
 I have no physical pain. It could be so much worse.
 But would the pain then signal to my body
 this is what to do this is why we're
 doing this.
 Instead abstractions and trying to
 tell myself I am tired because I'm sick
 not because I'm lazy
 not because I'm depressed.

if one more person says yeah I'm feeling
 so tired too I will fucking scream. Do you know that when
 you say this it's like pulling

a telephone out I have been carefully building to try and understand
 of the arch

that
 part
 this
 is
 not
 normal
 not to
 be seen
 different
 but so
 I can
 believe
 it.

9. Daily Notes - 2/6, 8 1/2" x 11", pen on paper, 2021

CHAPTER 10 RECORD

Time is told in the counting:

one more pill gone from one more bottle
one more shirt pushed across the floor
one more spoon sticking out from one more bowl

This is the compression of stillness

The space of time enclosed
is a shape that does change – only very slowly.
As noted,
each change
is noted.⁵⁰

There are many ways to make a painting. Some involve an underpainting and subsequent layers. Others are more direct, painting wet-on-wet. My first paintings that kindled a sense of *the rightness* in my body were made with only a palette knife – immediately responsive, thick in shape, color and expression.

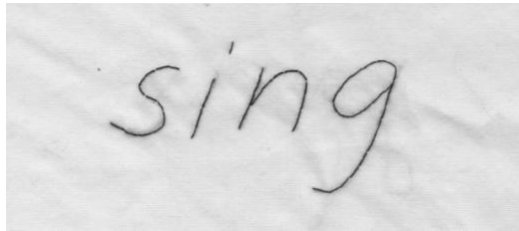
In my changing body, this immediate expressive response is inaccessible to me.

In part, it is that there is no way to express through my usual means. But also, there is something about the touch of my own hand that is painful to witness. I have always fallen back on drawing when I don't know what else to do. But somehow that kind of expression is not available. And by not available, I mean that it does not feel right. If I listen, *my body is a gauge*. It tells me things. The way that I draw is direct, responsive and non-verbal. The experience of my body is in my hands. And that, in this body-mind, is too exhausting and too close.

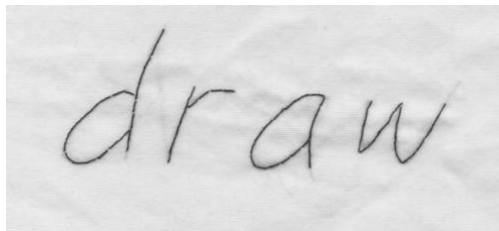
Drawing, like singing, is a direct extension of my body. I open my mouth and sound comes out without conscious thought. My body knows how to find the notes. Drawing, like singing, used to be a daily practice. In the *Daily Notes*, "draw" and "sing", each have only a single occurrence.

What are the safe ways of making? That open and invite without expectation of vulnerability? All things I make are of my body, but some are a direct line. These direct lines are now needed to stay inside; to fortify. They aren't ready to go out.

⁵⁰ Chenda Cope, "Time is told in the counting" (unpublished poem, December 2020), typescript.



10. *sing*, 2"x6", thread on sheet, 2021



11. *draw*, 2"x6", thread on sheet, 2021

The writing does what I could not in drawing.

Keeping its own time, writing became an affirmation of my own rhythms, a *reinscription* of change, while drawing felt a burden, a *reiteration* of the emotional pain of physical fatigue.

The *Daily Notes*, while still direct, were direct in a tenable way. The process of accounting helped me reach the place I could not get to before. Through observing my body and its motions, *other ways* began to open.

From this new place of access, I began to seek out *other ways* of documenting my time and space, developing the idea of *passive documentation* - objects that create a record of time and weight just by being. *The imprint of the weight of my body, of countless hours in bed. The oils of my skin on sheets. The mass of bowls as they stack up on my bedside table.* I eat a lot of soup and cereal these days. Soup because it's easy to digest and you can make a lot of it at once; cereal for when I don't have the energy to heat anything up.

Documenting these things is not actually passive. They require thought, intention and set up. But they begin with observation of what is already happening. Like a seismograph, their execution lies in the setup, recording the thing that is already happening.

The most *right*, as in *the rightness* of passive documentation that I have found so far, lies in pinhole photography. Because of the way they are constructed, pinhole cameras can be used for long exposures, as in multiple hours or even multiple days. Artist Regina Valkenborgh mounted a pinhole camera made from a beer can in an observatory where it was forgotten then found eight years later, having documented the night sky over the course of those eight years onto a single piece of photographic paper.⁵¹

I came to the idea of documenting time in a single frame in conversation with cohort member Avery. I was talking about the experience of the time shift that happens in the sick room – *Have I moved from this bed? Have I always been staring out this window? Has anything changed in the past four hours, days, weeks* – and we began to brainstorm ways of making this experience visible.

*crip time –
the inside
landscape;
inert*

Prior to this conversation I had been working with Professor Jeff Kasper on an embodied set of prompts to explore time as a space. In these pinhole photographs, *time is a space*.

*non crip time is
the moving
structure that
rebuilds around
you wherever you
go*

⁵¹ Woodyatt, Amy. "The 'longest-ever photo exposure' has been found -- inside a drink can." *CNN* online. Dec. 12, 2020. <https://www.cnn.com/style/article/can-eight-year-photo-intl-scli-gbr-scn/index.html>

Many moments compiled into one roomy image in which some things are recognizable but blurry, in which you just anchor yourself only to get lost again.

This is crip time.⁵² This is the closest I have come to visualizing my experience.



12. *untitled*, 3" x 6", photo on paper, 2021

I made several small pinhole cameras out of empty pill bottles. I loaded them with photographic paper and set them in different places around my house, primarily in my bedroom and the kitchen - the two spaces where I spend most of my time. Installing these cameras, I became attentive to the change in light throughout the day. Too much light and the long exposure doesn't work; the image comes out white, overexposed. It is from the in-between times of day, mid-morning, mid-afternoon, that these images come. The in-between times are especially hard. Not yet time for bed, not yet time for dinner. What to do with myself in-between. Isolated, inside, staring out that same window, the in-between time *starts to feel airless*.

⁵² Definition: *Crip* is a reclamation of the derogatory *cripple*, used by those within the disability community. *Crip time* is "the temporality of non-normative embodiments, from the day-to-day negotiations of moving from one space to another to the long view of historical time that has historically written disabled people out of the future." - Taraneh Fazeli, "Notes for Sick Time."

But

To set up the camera is to listen. It draws my attention to the way the light changes throughout the course of a day, tying my body back to the earth and the movement of the sun.

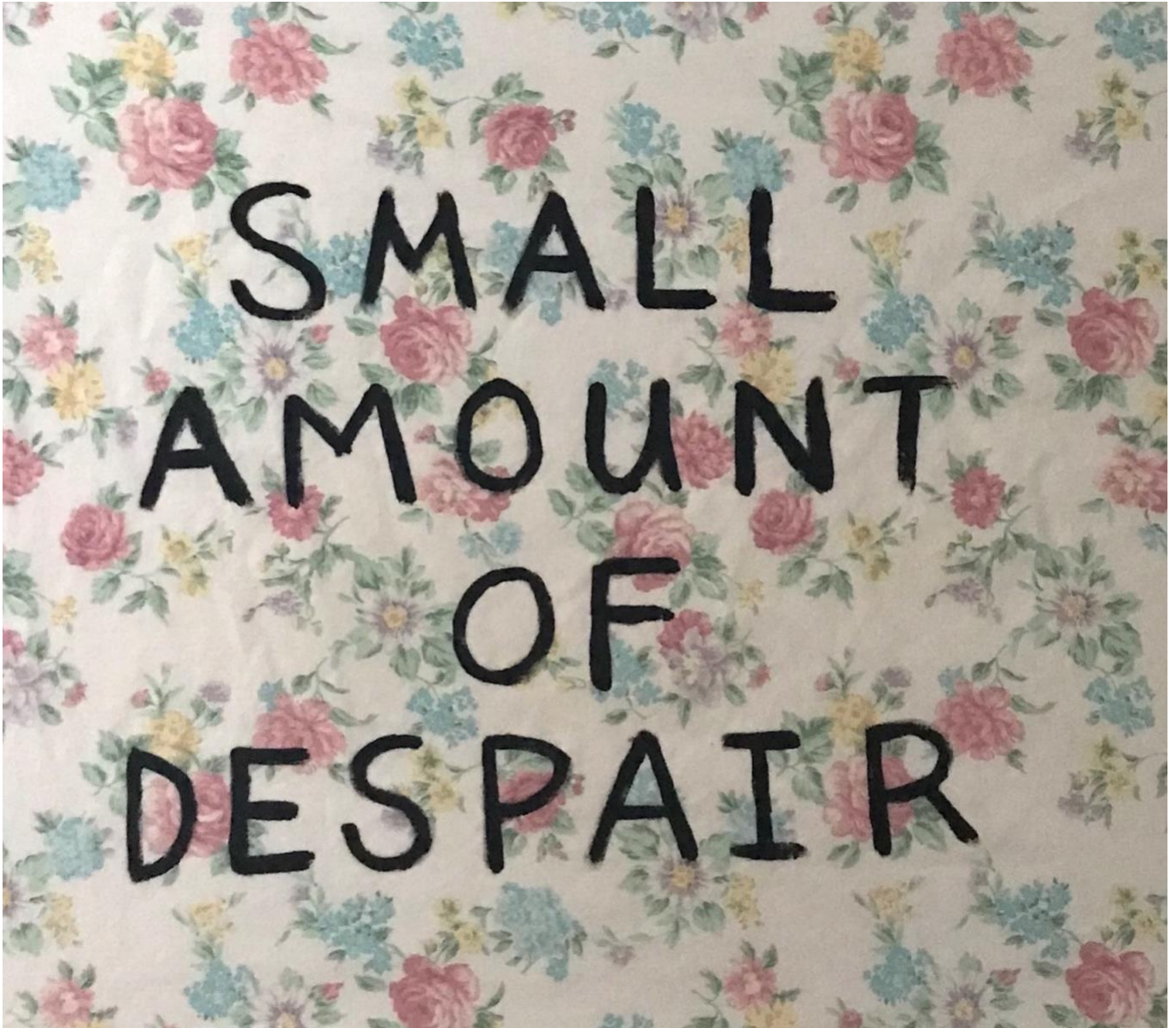
In 1971 Adrien Piper began *Food for the Spirit*, a series in which she photographed herself through the gaze of the mirror. Her body is just recognizable as is the camera, but the images are dark and murky, edges of her form get lost in the air.⁵³ She made these images during a time when she was immersed in studying Kant's *Critique of Pure Reason*. She describes the need to make them as a need to make visible a disappearing self - tying her mind back to the existence of her body.

I take these pinhole photographs to see a record of time as a space. I spend hours in bed, watching shapes of light bounce on the wall and shadows collect in corners. What do these hours look like as one single felt moment? Finding out was my original intention. They have also become another proof of life, an answer to *who knows where the time goes*, where my time goes? It is here, layer upon layer, built up in this room. My body is not visibly present, but these photographs do record the experience of my body.

If you knew the truth which you wouldn't unless the narrator told you, so they are telling you, so now you know the truth, which is that everything is made up of infinite thin layers, imperceptible even to those of us in-the-know. The narrator is still not sure about themselves.⁵⁴

⁵³ Adrien Piper, *Food for the Spirit*, gelatin silver prints, 1971.

⁵⁴ Cope, "Time Spaces – Prologue."



13. *(dis)Encouraging Banners*, 12" x 16", acrylic on sheet, 2021, detail

CHAPTER 11

BREAK

There are days when I learn nothing at all. There are days when my mind swirls and swirls around me.

These are the days for *Shut It Down*.

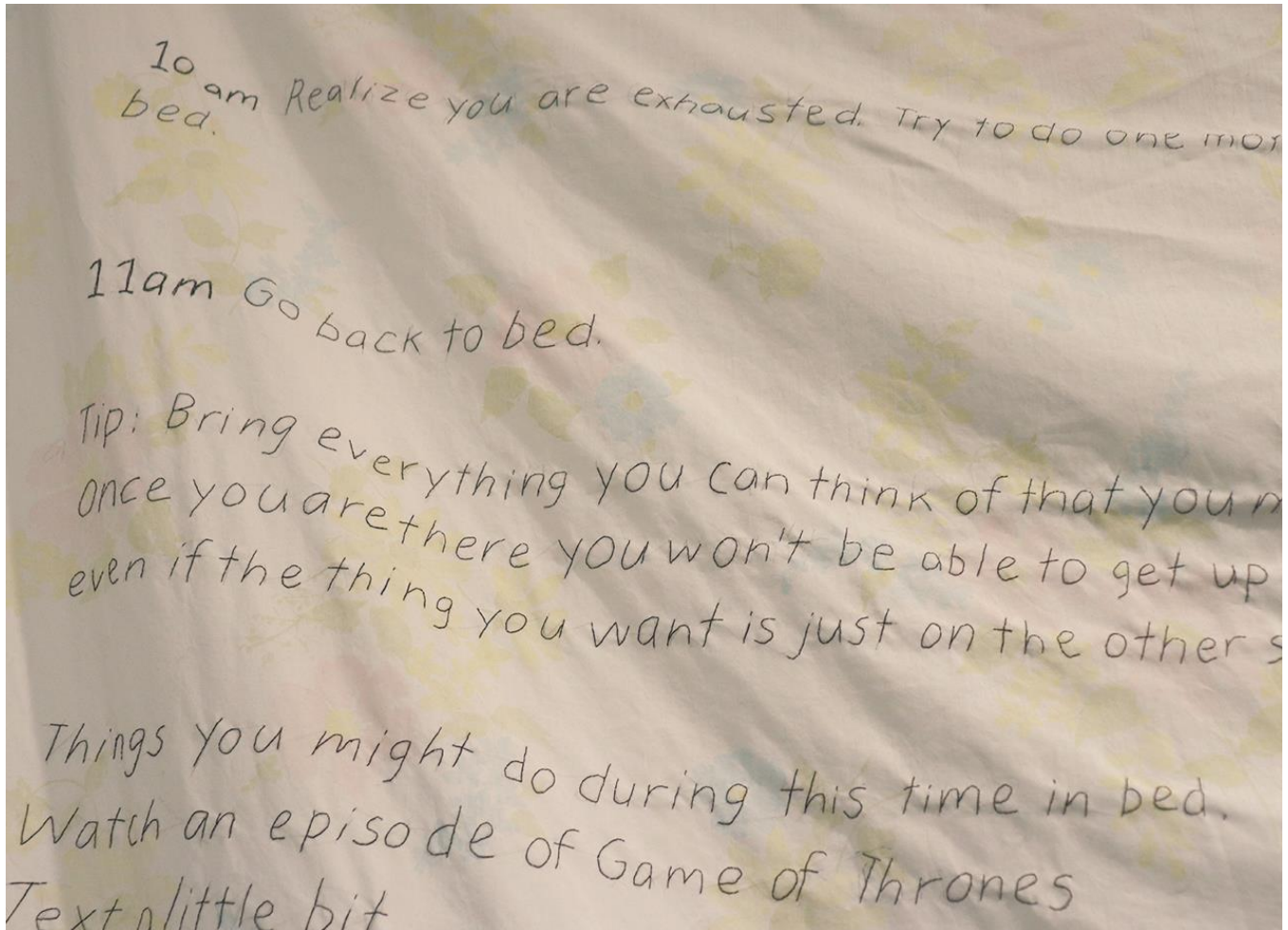
These are the days for *Sarah Lights a Candle For Me*.

Yesterday was one of these days. Exactly 30 days away from the install of my thesis show, I woke up exhausted from anxiety dreams about teaching (too many students showed up and I didn't know how we could socially distance). I knew it was a heavy day, one I couldn't lift and yet, I had a doctor's appointment and a studio visit. *Get (up), shower, make (food/drink), drive, park, go (to), walk, meet, look, listen, talk*. Adrenaline carried me through the doctor's appointment - turns out I have plantar fasciitis so now even slow walks are off the table, and an excellent studio visit carried me through the next part: *remember why I make art, talk about it in person with a real human*. By now it's 11:30 am and as I *clean (up)* and *put* my studio back in order, I *realize* that I *am* utterly exhausted. The exhaustion sinks into my stomach and burns behind my eyes. If it stayed in just my physical body, maybe that would be okay. I could listen to it, go home, rest, cuddle the cat. And in fact, these are the things I did. I was supposed to stay in town until 3pm to deinstall my work from the gallery. But Taylor had offered to do it for me so I called in that favor, stopped off at the pharmacy and drove home, finally getting into bed at around 2pm. And there I stayed for the rest of the day, breaking only to *pee, make (food/drink)*. And the cat slept on my lap while I watched at least six episodes of the X-Files, the perfect blend of government conspiracy theory, camp, suspense, bad-ass female lead and totally unlike my own reality enough to *Shut It Down*.

Why do I need this?
I will tell you.

On days like yesterday, I cannot see any light. I have had enough days like this to know that it will come again. But that knowledge is of no help in these moments. Neither is encouragement. Platitudes about *tomorrow is another day etc* do not help. I have found that by far the best thing to do is acknowledge that everything sucks and make the day go away. It is not useful for me to stew in the fact that I am angry, that I am in pain, that I am fucking exhausted, to feel the grief for all of the things I want to do but cannot. Those are things for today - after I have reset, after I have squeezed all of the time out of yesterday. In these

times there is only one thing to do - lie in bed and click the arrow forward button when the end of the show rolls around.



14. *Score for a Perfect Day*, 76" x 93", thread on sheet, 2021, detail

On days like this *hope becomes toxic*. Forget Awkward Acceptance. On days like this, I need my banner to read *a small amount of despair*. These banners give me permission to feel anger and grief. These banners help me allow my anger and my grief to surface. It does me the opposite of good to jump to silver linings. *Don't Skip Over This*.

Yesterday was *Shut It Down*
Today is *Don't Skip Over This*.

Today is grief for mixing plaster, grief for building structures, grief for sweat from physical labor, grief for sprinting as fast as I can to catch a frisbee, grief for splitting wood, for turning soil at the beginning of the season, grief for having a conversation longer than 45 minutes.

Today is anger, that walking fifteen minutes with a backpack on gave me plantar fasciitis. Anger, that my culminating work of three years of graduate school is about what I *(can't) do*. Anger, that my loved ones will not be able to come to the show. Anger that I feel all of these things. And anger and grief that I feel guilt for feeling all of these things.

And guilt does absolutely nothing other than to blot out all the other emotions, blocking them in, twisting around my insides, keeping me from the path of any kind of healing, collective or individual.



15. Sarah Lights a Candle For Me, dimensions variable, digital photograph, 2021

CHAPTER 12 SUPPORT

Until it was offered, I didn't even know I needed it: someone to tell when I am in the dark place. Someone who will not try to fix it, someone who will not try to convince me otherwise or offer words of wisdom. That person is Sarah - my best friend of 20 years. During a conversation one day when I managed to pick up the phone she said, *I'm going to light a candle for you. Anytime you are feeling this way, text me and I will light a candle for you.* Now she has candles at home and at work. When I need it I text *Candle*. She writes back *Done* and sends me a picture. If she's driving: *I'll light it when I get to work.*

What kind of instrument do you have right now? Would you be into recording a set length of "music" using some key and I'll do the same and then I'll mix them together? It can be a voice memo quality recording. Just hit record and play for at least seven minutes? In the key of? You pick if you accept...xo

-Travis⁵⁵

What are the safe ways of making?

Like the candle, this wasn't my idea. A few days later when I was feeling anxious and upset, I sat in my bed and sang mostly held notes in the key of B flat major for 7 minutes as a voice memo on my phone and texted it to Travis. He sent back an edited version, layering my recording with his - keyboard played in a bathroom at night while his family was sleeping. These are safe ways of making: This project that invites me to open my mouth and sing, holding me safely in a nook of care, a collaboration that holds us both in the ways we need to be held.

There is a net.

These collaborations are acts of care. They reach across time and space, connecting me with loved ones, creating a communication that is not of words. The text is a tool, bringing us from different physical spaces into time together. Through these acts we find one another. The instantaneous text combines with a mirrored physical action - creating an altogether new *time space* of presence and support. These friends create the spaces for me when I don't know how to for myself, all I have to do is show up. And showing up means reaching out.

sustain

to give support or relief to

nourish

⁵⁵ Travis, text communication with the author, March 26, 2021, 2:03PM.

They share in the record keeping. Together we go between private and public, building the archive of my chronically ill body.



16. Sarah Lights a Candle For Me, dimensions variable, mixed media, 2021

CHAPTER 13 PROCESS

What happens when we make the private chronically ill body public?

Each act of making has a process. The first step is that which is closest at hand: the clipboard above my bed, the set-and-forget camera, the text message, the low simmering pot. Over time this documentation of existence accumulates.

Each of these makings go through multiple layers before entering the public archive. This is not to *edit, clean (up) or hide*, the process is my learning curve, my body's slow integration of the proof.

What happens when we make the private chronically ill body public?

Like my illness, much of the process is invisible. It is made visible through slowness, through the acts of sustenance and support.

*"Slowing down...
focus on our
bodies...for its
intrinsic value as a
knowledge
producer."*⁵⁸

Stitch:

The act of stitching the words, so many hours reinscribing words already written. Through stitching they are repeated in thread as the needle pricks the tip of my middle and index fingers over and over again building a small callous as yet another repetition.

Print:

I spend hours in a rolling office chair in the Digital Print Center with Mikaël looking at the pinhole images. We lean back, we look at the images on the computer screen and print them one layer at a time, trying to achieve color, density, effects of contrast and shadows. They are like charcoal drawings, they are like monoprints. What began as *passive documentation* becomes *active process*. It is in the active process that the content binds itself to my internal knowledge. Days of sitting with these images, giving them their own time and space, with someone else's help, they begin to do their job.

*"art has a Real Job.
Everything that
touches or moves or
receives the degraded
is to be transformed
into that which saves
the planet/home. Art is
the arena and the table
of transformation."*⁵⁹

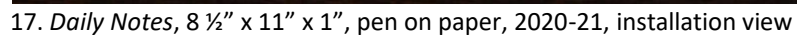
Count:

The verbs of *(not) doing* have a process. First documented, then extracted, listed and relisted, embroidered and rubbed with graphite

⁵⁶ Shajahan, "Being 'Lazy,'" 498.

⁵⁷ Ukeles, as quoted by Laura Raicovich, "The work we do" in *Mierle Laderman Ukeles: Maintenance Art*, ed. Patricia C. Phillips (Prestel Verlag, 2016), 7-9.

The *(not) doings* save me every day; their accumulation builds my belief.



CHAPTER 14

BEGIN

Stay. There is nowhere else to go.
Where you go, your body goes.⁵⁸

My body is a gauge. It does not want to tell anyone else who/what/how to do/be/perceive - it can only offer me to myself and I show that act to you, naming it as that.

Each verb is a kind of making. Each action, each component, constitutes my life each day.

What happens when we make the private chronically ill body public?

My body is present. My body is everywhere. It is here, with love and pain and imprint and echo, everywhere I go. Just as your body is present in love, pain, imprint and echo, everywhere you go.

The rightness is the feeling in the pit of the stomach, the sense of expansion in process. It is not the feeling that all is well or that everything is okay. Everything is not okay, everything is not well. *The rightness* is the sensation of truth in the process of being communicated.

Don't Skip Over This.
But You Don't Look Sick
A Burst of Light
Shut It Down
Hope becomes Toxic
Time is told in the counting
Sick time is non-compliant
The Life Instinct
I am tired
Sarah Lights a Candle For Me

⁵⁸ Cope, "My Material Body."

These are the loops that feed back into one another. I need to listen to every single one of them. When I listen to them, I am listening to my body. When I listen to my body, I am *part of* the larger healing project of all bodies. Sonya Renee Taylor: *It is through our own transformed relationship with our bodies that we become champions for other bodies on our planet.*⁵⁹ Healing begins here. It does not end here but it begins here.

⁵⁹ Taylor, *The Body is Not an Apology*, 5.

APPENDIX A SUPPORT

ESK's mom forwards her the NYT crossword puzzle daily. She sends them to me. ESK lives in Austin, TX. Her mom lives in New Hartford, CT. I live in Vernon, VT. Sometimes we have group texts about tricky answers.

Anne-Marie makes kitchari for me the first time, buying a surplus of ingredients and teaching me how to do it after she goes back to Philadelphia.

Jade's six-year-old Gus sends me an octopus stuffy to cuddle after Jade tells him that I spend a lot of time in bed.

Dad writes a poem and emails it to me.

Zach sends me giant t-shirt that says "Someone in Philadelphia loves you"

Shona repots a plant cutting and leaves it outside of my studio door.

Taylor deinstalls my work from Herter Gallery for me so I can go home to bed.

Avery brings me crutches and a boot when I develop plantar fasciitis.

Sarah lights a candle for me every time I text her the word "candle." These are days when I can't find any light. Texting Sarah is to share the darkness but also to remind myself that there is nothing left to do with this day but go into hibernation. (See Appendix B: *Shut It Down*)

Liana brings me an egg sandwich in bed.

Patrick reads my play and sends me back a detailed response with links to Dolly Parton videos.

JK Jourdan sends me a bubble mailer full of KN95 masks when she finds out that I'll be teaching in person.

Mom sends me a package with an easter egg and a card from my niece Riley saying "Just so you know I made you this egg. I love you."

Louie the cat sleeps on my lap while I embroider *Score for a Perfect Day*.

And so many more...

APPENDIX B SHUT IT DOWN

Sometimes there is nothing else to do but *Shut It Down*. What follows is a list of strategies and recommendations.

Soup: Make it when you have the energy and freeze in small containers.

Cereal: Get some, also milk and raisins.

Audiobooks: Always have one waiting in the wings. It's very hard to choose the next one when you are in this place. * Recommended genres = mystery and feminist sci-fi.

Books: same as above.

Crossword puzzles: print out and keep near your bed.

Words with Friends (smartphone app similar to scrabble): Play solo challenges because the games are shorter and the computer responds instantly.

Sudoku: for when words aren't working.

Blockudoku: for when numbers aren't working.

Embroidery/Quilting/Sewing/Knitting: anything that can be done from bed and is already in progress.

Winning Combination for when you need to shut it down but have some energy:

Audiobooks plus Embroidery et al

Winning Combination for when you need to shut it down and have no energy:

Watch a tv series that you are already in the middle of.

*This pretty much goes for everything. When you are exhausted and your mind is spinning it is impossible to make decisions. Know that these days are frequent and prepare for them.

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PHOTOGRAPH OF THE ARTIST



Chenda Cope, installing *Accumulations of (not) doing* in LEG Gallery, Studio Arts Building, UMass Amherst, May 12, 2021
Photograph by Avery Forbes